Using sedative substances until death: A mortality follow-back study on the role of healthcare settings

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Abstract: BACKGROUND: In the last decade, the use of sedative substances to keep a patient in deep sedation until death increased fourfold in German-speaking Switzerland, where every third patient admitted to hospital, palliative care unit or hospice died continuously deeply sedated. AIM: To investigate sedation practices across healthcare settings and to identify their associations with conventional symptom control. DESIGN: National mortality follow-back study in Switzerland between 2013 and 2014. Questionnaires on medical end-of-life decisions were sent to attending physicians of a continuous random sample of all registered deaths aged 1 year or older. SETTING/PARTICIPANTS: Of all sampled deaths, 3678 individuals who died non-suddenly and not through an external cause were included. RESULTS: Across settings, continuous deep sedation appeared more likely in patients aged younger than 65 years (odds ratio range: 1.53-2.34) and as part of or after intensified alleviation of pain and symptoms (odds ratio range: 1.90-10.27). In hospitals, sedation was less likely for cancer patients (odds ratio: 0.7, 95% confidence interval: 0.5-1.0, p = 0.022). In nursing homes, sedation was more likely for people who were married (odds ratio: 1.8, 95% confidence interval 1.3-2.5, p = 0.001). CONCLUSION: In all settings, sedated patients have significantly more pain problems compared to patients not receiving sedation. Large differences between settings seem to indicate different patient populations, different levels of professionals' palliative care experience and different availability of treatment options. Our study suggests that certain patient groups who may be as vulnerable to refractory pain and symptoms as others are less likely to receive continuous deep sedation until death when warranted.

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Using sedative substances until death: A mortality follow-back study on the role of healthcare settings

Sarah Ziegler[1], Margareta Schmid[1], Matthias Bopp[1], Georg Bosshard[2] and Milo Alan Puhan[1]

Abstract

Background: In the last decade, the use of sedative substances to keep a patient in deep sedation until death increased fourfold in German-speaking Switzerland, where every third patient admitted to hospital, palliative care unit or hospice died continuously deeply sedated.

Aim: To investigate sedation practices across healthcare settings and to identify their associations with conventional symptom control.

Design: National mortality follow-back study in Switzerland between 2013 and 2014. Questionnaires on medical end-of-life decisions were sent to attending physicians of a continuous random sample of all registered deaths aged 1 year or older.

Setting/participants: Of all sampled deaths, 3678 individuals who died non-suddenly and not through an external cause were included.

Results: Across settings, continuous deep sedation appeared more likely in patients aged younger than 65 years (odds ratio range: 1.53–2.34) and as part of or after intensified alleviation of pain and symptoms (odds ratio range: 1.90–10.27). In hospitals, sedation was less likely for cancer patients (odds ratio: 0.7, 95% confidence interval: 0.5–1.0, $p = 0.022$). In nursing homes, sedation was more likely for people who were married (odds ratio: 1.8, 95% confidence interval 1.3–2.5, $p = 0.001$).

Conclusion: In all settings, sedated patients have significantly more pain problems compared to patients not receiving sedation. Large differences between settings seem to indicate different patient populations, different levels of professionals' palliative care experience and different availability of treatment options. Our study suggests that certain patient groups who may be as vulnerable to refractory pain and symptoms as others are less likely to receive continuous deep sedation until death when warranted.

Keywords

Alleviation of pain, deep sedation, end-of-life practices, healthcare setting

What is already known about the topic?

- Population-wide studies have shown increasing prevalence rates of using sedative substances to keep a patient in deep sedation until death.
- There is no consensus among healthcare professionals regarding the conceptual definition and procedural understanding of these sedation practices.
- Empirical studies mostly focus on specialized palliative care settings, but it is known that a large share of continuously deeply sedated patients die outside specialized palliative care.

What this paper adds?

- This study identified certain patient groups that are less likely to receive sedative substances to be kept in deep sedation until death when warranted.

[1]Epidemiology, Biostatistics and Prevention Institute, University of Zurich, Zurich, Switzerland
[2]Clinic for Geriatric Medicine, University Hospital Zurich and Centre on Aging and Mobility, University of Zurich and City Hospital Waid, Zurich, Switzerland

Corresponding author:
Sarah Ziegler, Epidemiology, Biostatistics and Prevention Institute, University of Zurich, Hirschengraben 84, 8001 Zurich, Switzerland.
Email: sarah.ziegler@uzh.ch

- Across all care settings, the administration of sedative substances to keep a patient in deep sedation until death appears to be done primarily as part of or after intensified alleviation of pain and symptoms.
- Unmarried nursing home residents and hospital patients aged older than 80 years or diagnosed with cancer are less likely to receive sedative substances until death.

Implications for the practice, theory or policy

- Healthcare professionals should take care to provide sedative substances to all patients when warranted regardless of setting, age or diagnosis.
- Our findings point to the need for improved multidisciplinary collaboration and knowledge transfer to improve early identification of patients who could benefit from continuous deep sedation until death.
- To reach consensus on good clinical end-of-life care, more attention should be given to the management of refractory symptoms and the administration of opioids in terminally ill patients across different care settings.

Introduction

The provision of adequate relief of pain is a central aspect of medical care at the end of life. International findings reveal increasing prescribing rates of pain medication, with, for example, a more than twofold increase in prescription rates of strong opioids in Switzerland between 2006 and 2013.[1] There is substantial variation in prevalence estimates of pain between countries and study population, with trends increasing by age.[2–4] In end-of-life care, intensified alleviation of pain treatments are part of professionals' everyday clinical practice.[5] In Switzerland, physicians reported that more than three out of five patients dying non-suddenly received medication to intensively alleviate pain prior to death.[6–8]

Adequate symptom control is particularly challenging in terminally ill patients for whom all alternative treatment options have failed.[9] Where conventional symptom control is not sufficient, the administration of sedative substances can be considered.[10] According to a patient's need, the depth and duration of sedation vary from mild to deep and intermittent to continuously until death.[11] European general population studies have shown considerable variation regarding the overall prevalence of continuous deep sedation until death from 2.5% to 18.3%[12–14] with one of the highest increase observed in the German-speaking part of Switzerland (from 4.7% in 2001 to 17.5% in 2014).[6,15] In 2014, every third patient admitted to hospital, palliative care unit or hospice died continuously deeply sedated.[6] This variability in estimates are partly due to a lack of a common sedation definition stemming from different procedural and conceptual sedation understandings that are a function of physicians' specialties, patients' population, available resources and cultural and legal backgrounds.[6]

In specialized palliative care, the use of sedative substances intended to induce a patient's unconsciousness as an option of last resort when treating refractory symptoms is defined as 'palliative sedation'.[10] Palliative sedation is one of the most controversial issues in end-of-life care, as international variation in prevalence suggests different sedation practices.[16–18]

To ensure best clinical practice for palliative sedation in terminally ill patients, several guidelines have been developed.[19–21] In Switzerland, the first national guideline was released in 2005 by the Swiss Association of Palliative Care.[22] According to this guideline, palliative sedation, and particularly continuous deep sedation, until death is indicated only when terminally ill patient's unconsciousness is intended because no alternatives for palliation of refractory symptoms are available. Inappropriate sedation occurs when induced earlier than days or hours before a patient's death and medications other than benzodiazepines are used, for example, opioids.[10]

Despite these clinical guidelines, there is no consensus regarding the sedation definition and practice.[18,23,24] Previous findings indicate that, in specialized palliative care, the induction of patient's unconsciousness appears predominantly as primary intention, while outside specialized palliative care patient's unconsciousness was more often taken into account as a side-effect of intensified alleviation of pain.[25] Previous studies reveal that different sedation understandings and definitions have considerable consequences for how sedation is practised.[26] The extent to which existing population-wide prevalence estimates are indicative for setting-specific sedation types and how these are differentiated from conventional symptom control remains unclear.

Therefore, we aimed to identify patient and care characteristics associated with continuous deep sedation until death in different care settings. Furthermore, we aimed to investigate how decisions to intensify alleviation of pain and symptoms are associated with continuous deep sedation until death in different care settings.

Methods

Study design

We conducted a national mortality follow-back study on a continuous random sample of death registrations between August 2013 and February 2014 in Switzerland.

Under conditions of strict anonymity, we sent 8954 questionnaires to certifying physicians in all three language regions (German, French, Italian). The last completed questionnaire was received on 11 June 2014. The study was approved by the Zurich Cantonal Ethics Board (KEK-StV-Nr. 23/13). Written informed consent was not required because this study did not belong to the Human Research Act of the Swiss law. More details of the study methods including the questionnaire are given elsewhere.[7,8]

Questionnaire

If death was not sudden and unexpected, the case was considered eligible for questions regarding end-of-life decisions. Furthermore, to ensure that the respondents were actually the providers of the patient's end-of-life care, the first contact between the certifying physician and the patient had to occur before the patient's death. In such cases, physicians were asked whether they had (1) withheld or withdrawn a life-prolonging medical treatment taking into account the possibility of hastening the patient's death or explicitly intending to hasten or not to postpone the patient's death; (2) intensified the alleviation of pain and/or symptoms with drugs taking into account or partly intending hastening the patient's death or (3) prescribed or administered a drug with the explicit intention of ending the patient's life (physician-assisted death). For all patients with at least one end-of-life decision, physicians were asked to estimate how much their action had shortened life, from not life shortening up to more than 6 months of estimated shortened survival time.

Furthermore, we asked physicians if their patient received drugs, such as benzodiazepines and/or other sedative substances, to keep him or her in deep sedation or coma until death. To answer these questionnaires, physicians could access medical files.

Patient's demographics (age, sex, marital status) were available from death certificates and clinical characteristics (place of death, cause of death) from the questionnaire.

For the purpose of this study, we focused on intensified alleviation of pain and symptom treatments as particularly these can overlap with continuous deep sedation until death. For questionnaire, see Supplemental Material.

Analysis

We weighted all data to adjust for region-, age- and sex-related differences in response rates. Stratified binary logistic regression was used to calculate odds ratios (ORs), 95% confidence intervals (CIs) and *p*-values of potential determinants of the administration of continuous deep sedation until death (yes/no) in different care settings. To account for missing data in covariates (range 0.2%–1.3%), we performed multiple imputation. We calculated post hoc sensitivity analyses to assess the effects of interactions in order to identify significant differences between specific patient demographics, clinical settings and intensified alleviation of symptoms. All analyses were conducted using STATA IC for Macintosh (version 13.1, College Station, TX, USA).

Results

Study population

The sampled deaths represented 21.3% of registered deaths of people aged 1 year and above in the German-speaking Switzerland, 41.1% of registered deaths in French-speaking regions and 62.9% of registered deaths in the Italian-speaking region. In total, 8963 questionnaires were mailed to the certifying physicians, of which 5328 (59.4%) were returned until 11 June 2014. Of all certified deaths, 3678 were non-sudden and expected and therefore eligible for medical end-of-life decisions and continuous deep sedation until death.

Characteristics of patients continuously deeply sedated across healthcare settings

Across all healthcare settings, every fourth patient received sedative substances to be kept in deep sedation until death. Of these, the majority died in hospital ($n = 526$) or a nursing home ($n = 311$) and only a minority in specialized palliative care ($n = 60$) or at home ($n = 80$). Continuous deep sedation appeared to be done primarily together with intensified alleviation of pain and symptom treatments, particularly in nursing home and at home. In palliative care unit/hospice (31.1%) and hospital (21.3%), continuous deep sedation more often appeared without intensified alleviation of pain and symptom treatments compared to nursing homes (12.5%) and at home (11.2%). Although hastening of the patient's death was mostly taken into account for intensified alleviation of pain and symptom treatments (82.6%), physicians rarely presumed these treatments to be life shortening, particularly not in palliative care units or hospice (94.2%). In nursing homes (18.8%) and at home (22.5%), physicians more often intensified alleviation of pain and symptom treatments with the explicit intention to hasten the patient's death and thus more often presumed life-shortening effect.

As shown in Table 1, the distribution of patients' demographics varied between the different care settings. In specialized palliative care, continuously deeply sedated patients were younger (71.0 years) than in other settings, were more often female (64.6%) and were primarily diagnosed with cancer (76.4%). In contrast, in nursing homes, sedated residents were generally older than 80 years at time of death (80.8%), often widowed (49.7%) and

Table 1. Sociodemographic and clinical characteristics of 3678 non-sudden deaths and 977 patients continuously deeply sedated until death all over Switzerland 2013/2014.

	Non-sudden deaths, $N = 3678$	Patients continuously deeply sedated until death			
		PCU & hospice ($N_{tot} = 172$, $n_{CDS} = 60$)	Hospital ($N_{tot} = 1497$, $n_{CDS} = 526$)	Nursing home ($N_{tot} = 1539$, $n_{CDS} = 311$)	At home ($N_{tot} = 464$, $n_{CDS} = 80$)
	% (*n*)	% (*n*)	% (*n*)	% (*n*)	% (*n*)
Age in years, mean (SD)	78.3 (11.9)	71.0 (12.3)	74.1 (12.3)	84.1 (8.2)	75.5 (12.9)
1–64	11.6 (443)	28.5 (17)	23.2 (127)	3.4 (11)	20.7 (17)
65–79	24.8 (943)	42.2 (26)	38.0 (200)	15.8 (51)	29.4 (24)
80+	63.6 (2292)	29.3 (17)	38.8 (199)	80.8 (249)	49.9 (39)
Sex					
Female	54.7 (1963)	64.6 (38)	44.9 (233)	63.3 (194)	42.6 (34)
Male	45.3 (1715)	35.4 (22)	55.1 (293)	36.7 (117)	57.4 (46)
Marital status					
Single	10.3 (378)	8.8 (5)	11.7 (61)	9.3 (29)	7.3 (6)
Married	38.8 (1441)	44.3 (27)	53.4 (283)	31.3 (98)	58.7 (47)
Widowed	41.3 (1492)	27.3 (16)	25.3 (129)	49.7 (153)	29.0 (23)
Divorced	9.6 (363)	17.9 (11)	9.6 (53)	9.7 (31)	5.1 (4)
Other	0.02 (4)	1.8 (1)	0 (0)	0 (0)	0 (0)
Cause of death					
Cardiovascular disease	25.3 (904)	3.1 (2)	24.1 (126)	28.7 (88)	11.5 (9)
Cancer	29.6 (1152)	76.4 (46)	37.9 (200)	18.5 (58)	69.5 (56)
Pulmonary disease	10.6 (401)	6.8 (4)	11.6 (61)	13.6 (42)	5.0 (4)
Neurovascular diseases[a]	18.0 (642)	10.2 (6)	8.9 (46)	27.5 (87)	8.9 (7)
Other	16.5 (579)	3.6 (2)	17.5 (93)	11.8 (36)	5.2 (4)
Physicians' experience[b]					
0–2 deaths	12.8 (466)	0.0 (0)	9.6 (49)	8.6 (26)	26.2 (21)
3–9 deaths	50.3 (1804)	14.9 (9)	39.8 (209)	51.6 (161)	57.7 (46)
10+	36.9 (1372)	85.1 (51)	50.6 (265)	40.8 (123)	16.1 (13)
Artificial nutrition and hydration (ANH)					
No CDS	74.6 (2701)	NA	NA	NA	NA
CDS with ANH	7.3 (295)	13.9 (8)	46.2 (244)	10.1 (32)	13.9 (8)
CDS without ANH	18.1 (682)	86.1 (52)	53.8 (282)	89.9 (279)	87.1 (52)
Intensified alleviation of symptoms (APS)					
No APS	37.0 (1366)	31.1 (19)	21.3 (112)	12.5 (39)	11.2 (9)
APS only	11.7 (449)	11.8 (7)	10.0 (54)	8.1 (25)	12.3 (10)
APS combined with NTD	49.6 (1796)	50.4 (30)	66.3 (347)	75.8 (236)	70.2 (56)
APS combined with PAD	1.7 (67)	6.7 (4)	2.4 (13)	3.6 (11)	6.3 (5)
Physicians' intention of APS[b,c]					
Hastening of death taken into account	82.6 (1910)	87.9 (85)	84.7 (848)	81.2 (782)	77.5 (193)
Hastening of death intended	17.4 (402)	12.1 (11)	15.3 (153)	18.8 (186)	22.5 (52)
Estimated life shortening of APS[b,d]					
Not life shortening	64.3 (578)	94.2 (14)	58.4 (89)	48.2 (35)	42.9 (10)
Less than 24 h	14.2 (133)	5.8 (1)	16.4 (24)	22.2 (17)	28.2 (7)
Up to 1 week	16.3 (149)	0 (0)	20.0 (33)	20.8 (16)	25.0 (6)
Up to 1 month	3.6 (31)	0 (0)	4.7 (6)	7.2 (5)	0 (0)
Up to 6 months	1.2 (11)	0 (0)	0.5 (1)	0 (0)	3.8 (1)
More than 6 months	0.04 (3)	0 (0)	0 (0)	1.5 (1)	0 (0)

PCU: palliative care unit; SD: standard deviation; CVD: cardiovascular disease; CDS: continuous deep sedation until death; APS: intensified alleviation of symptoms; NTD: forgoing life-prolonging treatment decision; PAD: physician-assisted death; NA: not available.
Figures are column percentages and numbers. Percentages are weighted according to the age at 2014. *N* values are unweighted.
[a]Diseases of the nervous system including stroke and dementia.
[b]Missing data: 6 place of death; 36 physicians' experience; 123 continuous deep sedation until death; 193 APS intention and 270 estimated life shortening of APS.
[c]100% = all cases with an intensified alleviation of symptom decision.
[d]100% = all cases with an intensified alleviation of symptom decision and without an intended forgoing treatment decision.

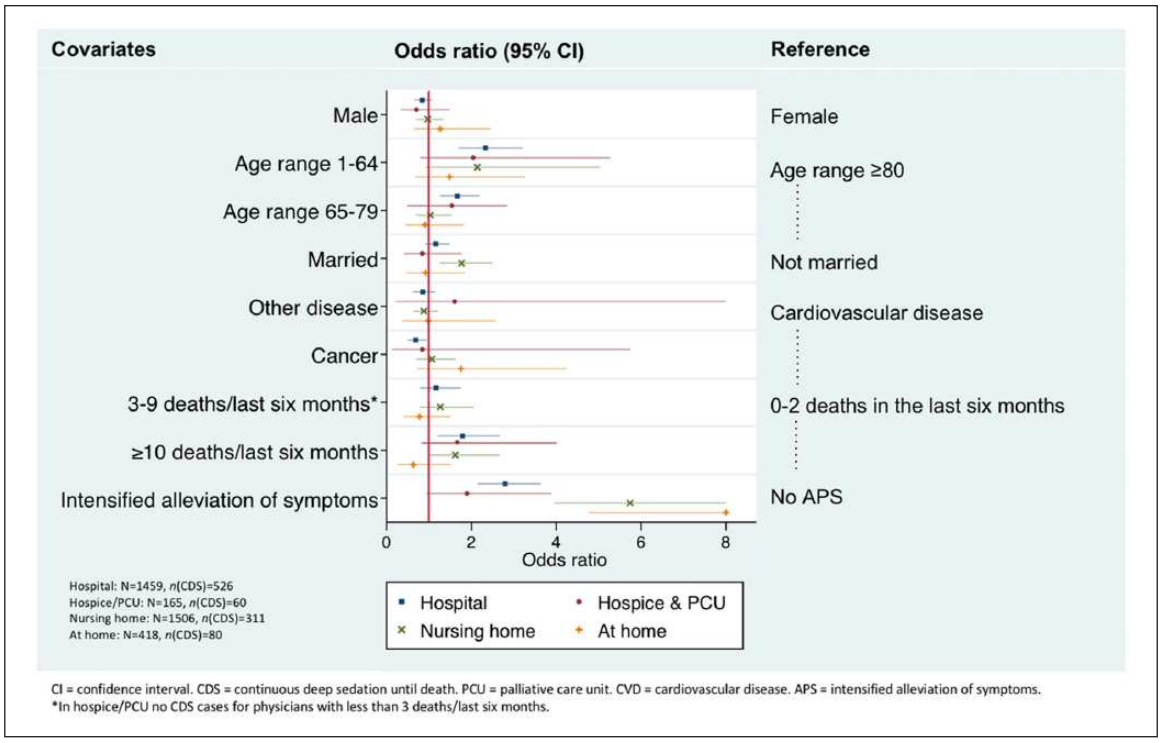

Figure 1. Association of continuous deep sedation until death with patients' socio-demographics, physicians' experience and intensified alleviation of symptoms in Swiss clinical practice 2013.

suffering of cardio- (28.7%) or neurovascular disease (27.5%). In hospital, sedation was less often provided to women, older patients and patients suffering from cancer. At home, continuous deep sedation was also provided more often to men.

Multivariate analyses

Multivariate analyses revealed that overall the administration of continuous deep sedation until death was more likely for patients aged less than 65 years (OR range: 1.53–2.34) and patients with intensified alleviation of pain and symptom treatments (OR range: 1.90–10.27; Figure 1). In hospital, continuous deep sedation until death was significantly less likely for cancer patients (OR: 0.7, 95% CI: 0.5–1.0, $p=0.022$), but more likely the younger patients were (65–79 years – OR: 1.7, 95% CI: 1.0–2.2, $p<0.001$; <65 years – OR: 2.3, 95% CI: 1.7–3.2, $p<0.001$) and the more experience a physician had with dying people (OR: 1.8, 95% CI: 1.2–2.7, $p=0.004$). In nursing homes, deep sedation was more likely for patients who were married (OR: 1.8, 95% CI: 1.3–2.5, $p=0.001$) and the more experience a physician had with dying people (OR: 1.6, 95% CI: 1.0–2.7, $p=0.054$). For details see Supplemental Material.

Discussion

Our study showed that the administration of sedative substances to keep a patient in deep sedation until death varied between healthcare settings. Across all care settings, continuous deep sedation until death appeared to be more often applied for patients aged younger than 65 years and as part of or after intensified alleviation of pain and symptoms. In hospital, sedation was less likely for patients suffering from cancer, but more likely the more experience a physician had with dying people. In nursing homes, sedation was more likely for people who were married and more likely the more experience a physician had with dying people.

The high prevalence of medical end-of-life decisions among sedated patients is consistent with previous findings from German-speaking Switzerland as well as internationally increasing trends of intensified alleviation of pain treatments and increasing prescribing rates for pain medication.[1,6,15] Findings from the Netherlands revealed that the use of opioids at admission to a specialized palliative care setting increased the probability of receiving continuous deep sedation.[27] This indicates that patients who receive continuous deep sedation until death have significantly more pain problems compared to patients not receiving sedation.[28] However, the extent to which a patient's pain was refractory and, therefore, represented an indication for continuous deep sedation remains under question. Today it is not clear what 'unbearable suffering' means and when a symptom is considered refractory, particularly in case of existential suffering.[29–31]

The observation that pain was associated with the use of continuous deep sedation furthermore might explain

the age differences we found. Although older patients seem more likely to experience unbearable pain symptoms, previous studies have shown that younger hospitalized patients are more likely to report pain and more likely to receive pain medication.[5] These findings are in line with the UK,[32] Italian,[33] Belgian[34] and Dutch studies,[27,35] pointing out a higher probability of receiving continuous deep sedation until death when aged younger, diagnosed with cancer and dying in hospital.

The age difference might further be due to selected patient populations. While cancer patients were often younger and more prevalent among continuously deeply sedated patients,[24] pain in older people and people with dementia is assessed less often and therefore underestimated.[5,36] The high prevalence of patients suffering of dementia in nursing homes highlights the significance of having a spouse in this setting, on top of the age effect. This could partly explain why older people in hospitals and those who do not have a spouse to advocate for them in nursing homes are less likely to receive continuous deep sedation.

In specialized palliative care and hospice, continuous deep sedation was less often reported to be combined with intensified alleviation of symptom treatments. Recent findings from Switzerland revealed that, outside specialized palliative care, healthcare professionals sometimes used opioids as a sole agent to either induce continuous deep sedation intentionally or to take sedation into account as a side-effect of increasing analgesics.[25] There is evidence that the more the palliative care experience healthcare professionals have, the more likely they differentiate continuous deep sedation from possibly life-shortening end-of-life decisions. In turn, less experienced healthcare professionals were more often ambivalent towards continuous deep sedation and thus more likely to consider it as possibly life shortening.[37–39]

The variation in sedation practice is not only related to professionals' palliative care experience but also to different resources provided by the clinical setting.[40] According to clinical guidelines, continuous deep sedation until death requires a multidisciplinary decision-making process with the option to call in palliative care experts, continuous administration of benzodiazepines and regular patient's monitoring.[10,20] But findings from Belgium indicate that the provision of multidisciplinary exchange, constant patient monitoring, intravenous infusions and access to sedative substances differ between healthcare settings.[18] Particularly, healthcare professionals working outside specialized palliative care have limited resources.

Our results serve as a starting point for developing a consensus on different types of sedation practices and its association with increased analgesia. However, some limitations need to be addressed in future studies. This study presented results based on retrospective self-reported sedation practices that are labelled as such by the attending physicians. Although we limited the time between a patient's death, death registration and sending the questionnaire to the attending physicians to a minimum, some recall bias cannot be ruled out. Furthermore, our results outline potential for sedation under- or overestimation. Thus, it is unclear to which extent different sedation incidence rates suggest different sedation practices and how they are differentiated from conventional symptom control. Our results highlight the strong association between continuous deep sedation until death and intensified alleviation of pain and symptom treatments. However, our data provide no conclusion about the extent to which sedation was used for symptom management. Future studies should complement the self-reported data with medical records and data from patients' file providing information on specific drugs used, their dosage, the time of administration, as well as previously attempted treatments.

Implications

Our results illustrate that continuous deep sedation until death is strongly associated with intensified alleviation of pain and symptom treatments. To bridge the gap between current guidelines and everyday clinical practice, more attention should be paid to the management of refractory symptoms.[41] Thus, sedation guidelines should also target the administration of opioids in terminally ill patients. In order to achieve consensus about good clinical end-of-life care, experiences need to be shared across healthcare settings. Therefore, multidisciplinary collaboration and education in symptom management should be improved. To increase a patient's quality of life, the early recognition of patients who could benefit from continuous deep sedation until death and thus advance care planning is required.[42] This would allow future studies to monitor eligible patients before continuous deep sedation until death is induced.

Furthermore, healthcare settings should be provided with professional and financial support to allow professionals to call in experts for decision-making and to provide constant patient monitoring needed for continuous deep sedation until death.

Conclusion

The healthcare setting plays a key role in understanding the variation in the administration of sedative substances, to keep a patient in deep sedation or coma until death. Across all settings, continuous deep sedation until death appears to be provided primarily as part of or after intensified alleviation of pain and symptoms. But the ability to speak up for oneself and report pain seems less likely with patients' increasing age and cognitive impairment. Therefore, unmarried patients in nursing homes and patients aged $\geqslant$80 in hospitals might be at higher risk of

not receiving continuous deep sedation until death when warranted.

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Declaration of conflicting interests

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Supplemental material

Supplemental material for this article is available online.

ORCID iD

Sarah Ziegler https://orcid.org/0000-0002-9907-5787

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